University of Massachusetts Worcester

Graduate School of Nursing

Childhood Asthma: Contextual Influences Affecting Family Management

A Dissertation Presented

By

Melissa A. Dunn

Approved as to style and content by:

_____
Donna J. Perry

_____
Susan Sullivan-Bolyai

_____
Kenneth Peterson

April 15, 2021
Date

_____
Joan Vitello PhD, RN, NEA-BC, FAHA, FAAN
Dean & Professor
University of Massachusetts Worcester
Graduate School of Nursing

Table of contents

Abstract

Purpose: The purpose of this study was to explore the way(s) in which family management of childhood asthma is affected by contextual influences as described in the Family Management Style Framework (FMSF) and to explore additional factors that affect family asthma management.

Specific Aims: The specific aims of this study were 1) to describe the everyday experiences of childhood asthma management within families, 2) to explore the way(s) in which family management of childhood asthma is affected by contextual influences (social network, care providers & systems and resources) as described in the FMSF, and 3) to explore additional sociocultural factors (supported by the literature but not currently described in the FMSF) that affect asthma management in families.

Framework: The Family Management Style Framework guided this study.

Design: A qualitative descriptive design was used to gather data from a purposive sample of female primary caregivers. Demographic data were collected, and individual interviews were conducted using a flexible interview guide.

Results: The findings support the contextual influences as described in the FMSF. An additional three contextual themes were identified: environment, emerging threats to health and work-life conditions. The themes are interrelated demonstrating the complexity of asthma management.

Conclusion: Family management of asthma is challenging and complex. The findings move towards understanding the connection between family asthma management and the social determinants of health. Nurses can support families managing childhood asthma by considering each of the contextual influences when planning interventions and working on policy initiatives that support the health of children with asthma.

Keywords: Family Management Style Framework, asthma management, COVID-19, contextual influences

Introduction to the Problem, Purpose and Specific Aims

It is estimated that 7 million children in the United States (US) have asthma (Akinbami et al., 2012). Asthma is a substantial financial burden in the US, costing 56 billion dollars in medical expenses, missed work, missed school days and premature death (Barnett & Nurmagambetov, 2011). Although people of all ages and backgrounds develop asthma some groups experience a higher prevalence and worse outcomes than others. Poverty is an independent risk factor for asthma prevalence, exacerbations and emergency department visits among children regardless of race or ethnicity (Keet et al., 2015). Hispanic and black children are disproportionately affected by asthma both in prevalence and severity when compared to white children (Akinbami, Simon, & Rossen, 2016; Mehta, Lee, & Ylitalo, 2013). Data also suggests that minority children with asthma use the emergency department (ED) more and have more hospitalizations (Keet, Matsui, McCormack, & Peng, 2017; Kenyon et al., 2014; Mehta et al., 2013), have greater readmission rates (Beck et al., 2014) and use fewer preventative measures (McDaniel & Waldfogel, 2012). In order to achieve health equity it is essential to examine both the medical and social conditions that lead to disparities.

A goal of Healthy People 2020 is to eliminate health disparities and achieve health equity (U.S. Department of Health and Human Services, 2014). This goal is in line with the nursing code of ethics as nurses are expected to advocate for equity in access to care and allocation of resources particularly for vulnerable populations (International Council of Nurses, 2012). A health disparity is a difference in health linked to social and/or economic disadvantage and is often associated with, but not limited to, race and socioeconomic status (U.S. Department of Health and Human Services, 2008). Early unfavorable health conditions may set people up for health challenges later in life that may have generational consequences (Chen et al., 2017).

Addressing childhood health disparities, such as asthma, has the potential to improve health outcomes across the lifespan.

Social disadvantage is implicated in contributing to chronic disease burden across the lifespan (Braveman & Gottlieb, 2014). In the medical literature the definition of social disadvantage refers to a person's position in a social hierarchy with people being separated by economic resources, race, ethnicity, gender, sexual orientation and disability (Braveman, 2014; Braveman, 2006). For this study social disadvantage will refer to individuals and families at risk for bias, marginalization and/or unequal access to resources based on race, ethnicity and/or economic status. Social disadvantage is recognized as contributing to poor asthma control in children (Kopel, Phipatanakul, & Gaffin, 2014). Families experiencing social disadvantage, due to socio-economic status (SES), race and/or ethnicity, likely experience multiple stressors that contribute to poor asthma outcomes.

The family's ability to manage a child's asthma is likely influenced by social and environmental factors often overlooked in research (Sato et al., 2013). Asthma affects not only the child with the condition but the entire family. For example, a family may experience financial strain due to a parent missing work to care for a sick child. Therefore, it is important to understand how the family as a unit manages a child's asthma but also the way(s) in which the family is affected. Families are defined in this study as "a group of intimates living together or in close geographic proximity with strong emotional bonds (identification, attachment, loyalty, reciprocity, and solidarity), and with a history and future" (Fisher et al., 1998). With a strong body of existing literature describing health disparities experienced by low income and/or minority children with asthma, the next step is to examine the ways in which conditions of social disadvantage affect the family's ability to manage a child's asthma. Social disadvantage may be

aligned with what is referred to as contextual influences in the Family Management Style Framework (FMSF) that will be used to guide this dissertation study. Contextual influences are factors that exert and contribute to ease or difficulty of family management such as social and peer networks, community and financial resources, health insurance access, cultural practices and beliefs and access to and relationships with healthcare providers (Deatrick et al., 2006; Knafl, Deatrick, & Havill, 2012).

There is a shortage of literature, including nursing literature, describing the ways in which contextual influences affect asthma management in families experiencing social disadvantage. Nurses interact with children with asthma and their families in a number of settings and are situated to integrate both medical and social considerations into care. It is critical for practice to be research-based in order to optimize outcomes for families facing social disadvantage. This study is a necessary step in understanding how to best support vulnerable families to successfully manage a child's asthma. Therefore, the purpose of this study is to explore the experience of managing a child's asthma in families experiencing social disadvantage.

The specific aims of this study are: 1) to describe the everyday experiences of childhood asthma management within families experiencing social disadvantage 2) to explore the way(s) in which family management of childhood asthma is affected by contextual influences (social network, care providers, systems and resources) as described in the Family Management Style Framework 3) to explore additional sociocultural factors (supported by the literature but not currently described in the FMSF) that affect asthma management in families experiencing social disadvantage.

Theoretical/ Conceptual Framework

Family Management Style Framework

The Family Management Style Framework (FMSF) seeks to explain the ways in which families integrate management of a chronic condition into everyday family life (Knafl et al., 2012). The FMSF was first published in 1990 with the most recent revision occurring in 2012 (Figure 1) (Knafl & Deatrick, 1990; Knafl & Deatrick, 2003; Knafl et al., 2012). Refinement of the framework has occurred as literature concerning family management of chronic conditions has evolved and updates to the FMSF reflect contemporary research findings (Knafl & Deatrick, 2003; Knafl et al., 2012). The most recent update of the FMSF reflects a change in language from "sociocultural context" to "contextual influences" (Knafl et al., 2012). The contextual influences, as described in the revised FMSF, include: social network, care providers and systems and resources (Knafl et al., 2012). The authors have also updated the framework to reflect a broader definition of family and replaced the terms child, mother, father and siblings with more general terms (person with condition and individual family members) (Knafl et al., 2012). These changes allow use of the framework across the lifespan and with a variety of family structures.

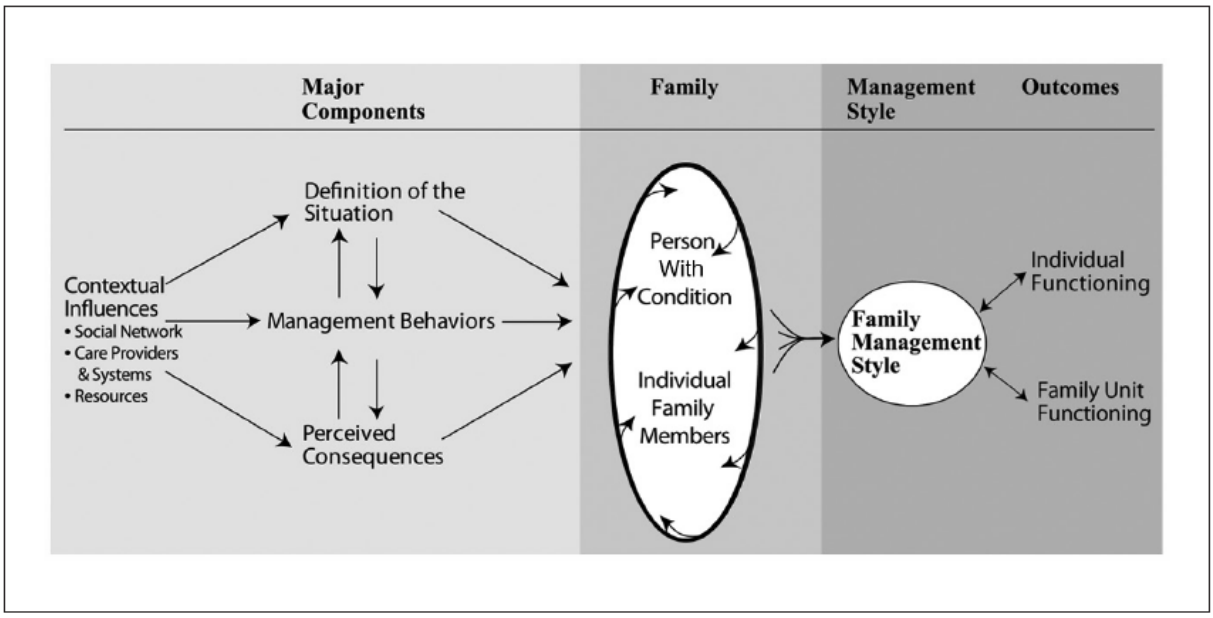


Figure 1: Revised Family Management Style Framework.
From "Continued Development of the Family Management Style Framework," K.A. Knafl, J. A. Detrick and N.L. Havill, 2012, *Journal of Family Nursing, 18*, page 25.

The FMSF consists of three major components and eight underlying dimensions (Knafl et al., 2012) as shown in Table 1. The major components are *definition of the situation*, *management behaviors* and *perceived consequences*. Definition of the situation refers to the parent's view of both the child with the condition and the illness in terms of how the condition is integrated into daily living. Management behaviors refer to the family's approach to managing the child's condition. Perceived consequences reflects both the present effect the condition has had on family life and the anticipated effect the condition will have on the child and family in the future. Some of the definitions of the underlying dimensions were revised in the most recently publication of the FMSF (Knafl et al., 2012). A brief description of each dimension, based on the updated FMSF, is provided in Table 1.

Table 1: Major Components and Underlying Dimensions of the FMSF

Major Component	**Underlying Dimensions**
Definition of the Situation	Child Identity: parent's view of the child and condition and parent's focus on the condition, normalcy, capabilities or vulnerabilities View of Condition: Parent's beliefs about the condition (cause, seriousness, predictability and course) Management Mindset: Parent's belief regarding the ease or difficulty regarding the treatment regime and their ability Parental Mutuality: Parent's beliefs about shared or differing views regarding the child, illness, parenting philosophy and condition management
Management Behaviors	Parenting Philosophy: The overall approach to condition management including goals, priorities, values and beliefs Management Approach: Parent's view of their own and their child's daily routine and strategies for managing the condition and incorporating it into everyday life
Perceived Consequences	Family Focus: The parent's perception of how management of the condition has been incorporated into family life Future Expectations: Parent's beliefs regarding the condition's implications for their child's and family's future.

Sociocultural factors are recognized as influencing family management (Knafl et al., 2012). Contextual influences (social networks, care providers, health care and education systems and resources) are the sociocultural factors that may influence the ways in which a family responds to a child's chronic condition and are likely to influence the family members' definition of the situation, management behaviors and perceived consequences (Knafl et al., 2012). Further examination of the ways in which contextual influences affect family management of chronic conditions has been identified as an area of the FMSF requiring further development (Barakat, 2012; Knafl et al., 2012). The emerging nature of the contextual influences in the FMSF leaves

room for further exploration. Knafl, Deatrick & Havill (2012) acknowledge that the contextual influences are the most underdeveloped aspect of the FMSF. For this reason, the contextual influences will be explored in this study to better understand the ways in which social disadvantage affects the everyday life of families managing asthma.

Background and Significance

Asthma

Asthma is a chronic disorder affecting the airway leading to inflammation, airway obstruction and hyperresponsiveness of the bronchia (National Asthma Education and Prevention Program, 2007). In the United States, it is estimated that there are 7 million children with asthma (Akinbami et al., 2012). The disorder exists on a continuum that can range from mild to severe persistent asthma (National Asthma Education and Prevention Program, 2007). Treatment varies depending on severity and individual response. Management of asthma may include peak flow monitoring, pulmonary function testing, trigger avoidance, managing environmental irritants, symptom monitoring, long-term control and/or quick-relief medications (National Asthma Education and Prevention Program, 2007). One of the primary roles nurses play in prevention and treatment is to ensure caregivers and children with asthma understand the goals of treatment. Nurses also collaborate with families in development of strategies to effectively manage maintenance care and respond to exacerbations. In order to effectively provide family focused care, nurses and other healthcare providers need to understand the challenges families face beyond the medical management of asthma. Sato et al. (2013) identified the need to assess non-illness specific dimensions of the family and home environment recognizing the potential to provide interventions targeting non-illness related aspects of family asthma management. Good asthma control will likely result in fewer missed school and work days, reduce the financial

burden associated with exacerbations and allow the family to focus on other important aspects of family life.

Family Asthma Management

Family management is the integration of condition management into a family's daily life (Knafl et al., 2012). There have been few studies framing asthma management within the context of the family unit (Gibson-Young, Turner-Henson, Gerald, Vance, & Lozano, 2014; Sato et al., 2013). Families in which a member has a chronic illness, such as asthma, must take measures to manage the illness daily and respond to exacerbation when they occur. The family's ability to successfully manage a child's chronic condition is essential to the child's well being. Contextual factors and social determinants of health are influences on family asthma management. For families experiencing social disadvantage there may be additional challenges that are not well understood.

Understanding the contextual factors (social network, care providers, health care and education systems and resources) and the ways in which they relate to family asthma management will provide data necessary to develop sound clinical interventions and public policy to support the families most in need. There are influences that are known to affect asthma morbidity such as exposure to environmental pollutants and exposure to violence (Williams, Sternthal, & Wright, 2009) yet their perceived impact on family asthma management is unknown. It is speculated that these conditions of social disadvantage place physical and psychological stress on children with asthma and their families, which influences morbidity (Kopel et al., 2014). It is unclear how these factors fit into the current FMSF. For this reason, additional influences informed by the social determinants of health and supported by current literature, will also be explored.

There is also a gap in the literature with regard to understanding the impact of asthma management on the family as a whole. Current qualitative research consists mainly of maternal interviews focused on education needs, beliefs about management and home environment. The proposed study will describe the experience of managing asthma from the perspective of additional family members. Additionally, the perceived influence of contextual factors on family asthma management as described by individual family members experiencing social disadvantage will be explored.

Contextual Influences

There are clear gaps in the literature surrounding the ways in which families experience social disadvantage and how it affects asthma management. By exploring the contextual factors related to asthma management, a deeper understanding of the ways in which families experience social disadvantage will emerge. Resources, social networks, health care providers, healthcare and education systems have been identified as influencing chronic disease management in families (Knafl et al., 2012). Some families are particularly vulnerable to poor health outcomes linked to social disadvantage. Complex and related social and environmental challenges have been linked to poorer asthma outcomes in children including; poverty, race/ethnicity, neighborhood quality, income inequality in neighborhoods, exposure to violence, chronic stress and exposure to pollutants to name a few (Kranjac et al., 2017; Williams et al., 2009). The contextual influences described in the FMSF link to a growing body of literature related to the social determinants of health; the conditions in society and the environment that affect health, functioning and quality-of-life (Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for, 2020, 2010). Deatrick (2017) has noted a lack of emphasis regarding the role of family in the social determinants of health. She recently raised the

important question of how families are impacted by the social determinants of health and encouraged further exploration in nursing research. There is likely overlap between the contextual influences described in the FMSF and the social determinants of health framework. Influences such as violence, racism, housing and income inequality do not clearly fit in the current FMSF, therefore the social determinants of health may help in framing influences whose placement in the current framework is unknown.

For families experiencing social disadvantage, the challenges related to contextual influences may be overt (e.g. inability to afford medications) or subtle (e.g. affect of chronic stress on asthma morbidity). There are currently no studies with a primary purpose of examining contextual influences and asthma family management as described in the FMSF. There have been studies that begin to describe the ways in which contextual influences may affect asthma management in children and/or families yet there are areas in need of further exploration. The studies discussed below support the assertion that family asthma management is connected to contextual factors and the gaps in the literature will be further described.

Social network. Social networks are the people outside of the family who can either hinder or support a family managing a chronic illness (Knafl et al., 2012). When a primary caregiver is unavailable other family members or support people may not have the skill/ability to appropriately respond to symptoms of an asthma exacerbation or provide maintenance medications and/or avoidance of triggers. Children with asthma reportedly had poor asthma control and more emergency room visits when their mothers worked outside the home (Gibson-Young et al., 2014). Potential contextual influences such as parent work patterns and paid time off may impact family asthma management. Family and schools have been identified as a source of support for children with asthma and both children and parents expressed the value of having

people in their community with the ability to help during an exacerbation (Martin, Beebe, Lopez, & Faux, 2010). Examination of support systems and the context within which a family lives can provide details necessary to implement appropriate interventions.

Care providers, health care and educational systems. The interactions families have with health care providers, educators and the larger systems in which they are situated have an influence on family management of chronic conditions (Knafl et al., 2012). Dowell (2015) explored the experiences, functions and needs of low-income African American mothers of children with asthma and found that "competent healthcare providers" was a theme that emerged as important to asthma management. Grineski (2008) found that mothers of uninsured children identified school nurses as key to assisting them with asthma education and management but also in helping families sign up for health insurance and assisting them obtain items such as clothing and diapers when financial resources were limited. The mothers in this study also indicated that language barriers were problematic when the parent spoke Spanish and the nurse was English speaking. Fathers of children with asthma report challenges in the school setting related to avoidance of triggers and policies that do not allow children to carry their medications with them (Cashin, Small, & Solberg, 2008). It appears that care providers and school systems can be either a source of support or frustration for parents managing a child's asthma.

Resources. Financial resources and health care coverage are identified as influencing chronic disease management in the FMSF (Knafl et al., 2012). In children, greater asthma related inflammation and impairment has been found to be associated with low SES (Chen et al., 2011). Beck et al. (2014) found that low socioeconomic status (SES) and hardships explained 48.5% of the readmission disparities experienced by African American children when compared to white children. Minority children in low-income families are particularly vulnerable to poor asthma

outcomes (Beck et al., 2014; Chen et al., 2011). Children experiencing food insecurity have higher odds of also having asthma (Mangini, Hayward, Dong, & Forman, 2015). Additionally, for children living in households below the poverty level the association between food insecurity and asthma are stronger (Mangini et al., 2015). These findings reinforce the belief that social barriers, including financial hardship, contribute to asthma disparities. Interestingly, perceived financial burden appears to influence asthma outcomes as well. Patel, Brown & Clark (2013) found that regardless of access to care, parents' perception of financial burden was associated with worse asthma outcomes including emergency utilization and missed school days. Development of interventions intended to reduce asthma related disparities for children belonging to socially disadvantaged groups, need to account for challenges that transcend medical management and take into account access to and availability of resources.

In summary, this research will explore the management of a child's asthma within families experiencing social disadvantage. Currently, family asthma management literature is primarily focused on the maternal experience, education needs, beliefs about management and home environment. This study will address a critical gap in the current body of literature by exploring the perceived role of contextual influences and additional sociocultural factors in family asthma management. Nurses play an important role in supporting families not only with the medical management of asthma, but also assisting families with the non-illness dimensions of managing a chronic illness. In order to fully appreciate the complex dynamics related to asthma management in families experiencing social disadvantage qualitative description will be the method used.

Methods

Qualitative Description

Qualitative description is a research method rooted in naturalistic inquiry (Sandelowski, 2010; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). Sandelowski (2010; 2000) describes qualitative description as a method distinct from other qualitative methods, though it shares characteristics common to other qualitative approaches. Qualitative description results in findings that are close to the data without deep interpretation of the data provided by participants also referred to as "data-near" (Sandelowski, 2010). The presentation of the data after analysis should be written in a way that is easy to understand and often uses the participants' own words (Willis et al., 2016). Qualitative description is useful in the study of vulnerable populations when attempting to better understand the social and cultural contexts that contribute to health disparities (Sullivan-Bolyai, Bova, & Harper, 2005). Qualitative description gives voice to those experiencing health disparities by using the participants' own words to suggest ways in which care might be improved (Sullivan-Bolyai et al., 2005). Qualitative description is suited to this study because the research question is focused on the participants' experiences and description of family asthma management. This study will explore, contextual influences, an underdeveloped area of the FMSF. Qualitative Description using directed content analysis is an appropriate approach for validating and/or extending a theoretical framework (Hsieh & Shannon, 2005).

Sample

This study will utilize purposive sampling (Lincoln & Guba, 1985). Family will be the unit of analysis for this study. This study will include primary caregivers as well as additional family members involved in the child's day-to-day management as informants. Multiple informants improve internal validity when the family is the unit of analysis (Lynn, 1995) since the family is more than simply a sum of its parts (Gilliss, 1983). Primary caregivers and additional family members over the age of 13, who participate in management, will be invited to

participate in individual interviews. Families will vary is size and structure therefore the number of participants from each family will vary. Initially, interviews with approximately 25 individuals across approximately 8-12 families will be conducted. This will allow the researcher to begin to analyze data both within and across families. Enrollment and data collection will occur until informational redundancy and data saturation has occured (Lincoln & Guba, 1985). Additional interviews will be conducted with additional families as necessary to reach data saturation. Up to 100 individuals may be interviewed. Participants will be recruited from urban community based clinics serving a diverse population including low-income families. In an effort to recruit participants with diverse ethnic backgrounds and to better understand the experiences of the local population, interviews will be offered in both English and Spanish. Snowball sampling will be used to recruit within the family (Lincoln & Guba, 1985). For example, a primary caregiver agreeing to participate in the study may invite other family members to participate. The researcher will ask participants to share her telephone number with family members who may be interested in participating. They will be asked to call the researcher to discuss participation. The researcher will not collect names or telephone numbers of potential participants from family members.

Primary caregiver participants will be:

- Primary caregivers for a child (2-12 years-old) with a medical diagnosis of asthma. Primary caregivers will be defined as providing at least 50% of the direct care and decisions related to the affected child's health related care.
- Age 16-years or older
- Able to speak English or Spanish

Family participants (not considered a primary caregiver) will be:

- Identified as a family member by the primary caregiver and be able to provide insight into family management of asthma
- Age 13-years or older
- Able to speak English or Spanish

Exclusion criteria will include:

- Individuals not able to communicate in either English or Spanish
- Primary caregivers under the age of 16
- Additional family member younger than 13 years of age
- Individuals with cognitive limitations who are not able to provide consent/assent

Setting

The first site is a family community health center located in Worcester Massachusetts and affiliated with an academic medical center. The family health center provides primary care services to nearly 2,000 patients. The clinic was initially established to meet the public health and primary care needs of families living in low-income housing in the city of Worcester. The clinic provides services in both English and Spanish. In addition to primary care, this site manages patients with a number of chronic conditions and is involved with community outreach activities. The second site is a non-profit community health center located in Worcester Massachusetts with multiple locations in and around Worcester. The health center provides primary care and a variety of specialty services to approximately 26,000 people of diverse racial and ethnic backgrounds. Approximately 95% of the patients are reported to be low-income and 29% were reported to be uninsured. These settings were selected to maximize recruitment of families with low incomes and those with diverse racial and ethnic backgrounds. The researcher has permission to recruit participants from the medical director of the first site and will submit a

formal request to recruit participants from the second site. A “Research Proposal Questionnaire” will be submitted to the Quality Care Committee at the health center.

In the event that the researcher is unable to enroll enough participants to reach data saturation in a timely manner at the first two sites, the Conquering Diseases program is available to UMass researchers through the University of Massachusetts Center for Clinical and Translational Science. The program maintains a clinical research volunteer registry, community resource center and provides consultation services to researchers.

Recruitment Procedures

Participants will be recruited from two community based health centers and via the Conquering Diseases Program at UMass Medical School. Participants will be primary caregivers (at least 16 years of age) for a child with asthma and additional family members (at least 13 years of age) who also participate in family asthma management. Recruitment flyers will be available at each site for providers, nurses and community health workers to distribute to primary care givers and/or family members of children with asthma. Prior to distribution of recruitment flyers, the researcher will request the opportunity to meet with staff members as the community based centers to describe the study, answer questions and develop a rapport with providers and staff. Recruitment flyers will be available in both English and Spanish and include the researcher’s contact information. Interested participants will contact the researcher directly to learn more about the study. Participants who would like to participate and meet the inclusion criteria will arrange a mutually agreeable time and location to review the informed consent. The researcher will also provide recruitment flyers to family caregivers to share with additional family members that may be able to offer insight into the family’s asthma management. Interested family members will be able to contact the researcher directly.

The Conquering Diseases program offers several options for sharing study information with potential participants. This study has the potential to be listed as a currently enrolling study on the Conquering Diseases website and in their monthly newsletter. The Conquering Diseases program also assists with study recruitment by providing study information at community events and in their study suite. The researcher may also request access to the volunteer registry for individuals meeting the inclusion criteria.

Data Collection Procedures

Data collection will include audio recorded, face-to-face individual interviews, researcher observations and demographic data. Participants will be interviewed one time with both interviews and demographic data collection occurring at a single session. Interviews are expected to last approximately sixty minutes. Interviews will be conducted in a mutually agreeable location that offers privacy to the participants. Semi-structured interviews will be conducted using flexible interview guides. The parent/guardian interview guide (Appendix A) and family member interview guide (Appendix B). Two interview guides were created in order to frame the questions appropriately for the participant's role within the family. The researcher will also record observations made during the interview in field notes. Field notes will be written shortly after the interview and will be included as data. Two audio recorders will be used to reduce the chance of data lost to recorder malfunction. Demographic data will be collected verbally by the interviewer and recorded on a paper demographic data collection form and later entered into Microsoft Excel. Verbal collection of this data will be used since the literacy level of the participants is unknown. There will be separate demographic data collection forms for parents (Appendix C) and for the other family member participants (Appendix D). The use of two demographic instruments eliminates unnecessary duplication of information (e.g. age and gender

of the child with asthma). This will reduce the burden on the participants and also reduce the chances of participants providing conflicting information. Individuals indicating Spanish as their primary language will be offered the use of a Spanish interpreter for the interviews since the researcher is not fluent in Spanish. Cross-language research refers to the presence of a language barrier between researcher and participant (Temple, 2002). For this study, professional Spanish interpreters or bilingual community health workers with medical interpretation training will be used. Interpreters will at a minimum have sociolinguistic competence (Squires, 2008). The researcher will discuss expectations related to the interview process with interpreters (Kosny, MacEachen, Lifshen, & Smith, 2014) in order to elicit quality data and minimize threats to validity in this cross-language study (Santos, Black, & Sandelowski, 2015).

Data Management

Electronic data will be stored on the UMass Medical School server in a research drive, which is backed up each night. The electronic data stored on the research drive will be password protected and will be accessible to the PI and dissertation committee. Audio recordings, transcribed interviews, field notes, memos, deidentified demographic data will be stored on this protected drive. A professional transcriptionist will transcribe audio-recorded interviews. Transcribed interviews will be reviewed and compared to the original audio recordings for accuracy. Audio files will be deleted once transcription accuracy is confirmed. Participants will have a unique identifier only known to the researcher. The unique participant identifier will be linked with the participant's name and stored in a locked cabinet away from any other study data or documents. Demographic data will be collected by the researcher on a printed copy of the collection tool and then entered into Microsoft Excel as deidentified data. Double entry of data will be performed as a way of ensuring accurate data entry.

Data Analysis

Directed content analysis will be used to analyze transcribed interview data and identify themes (Hsieh & Shannon, 2005). Data collection and data analysis will occur concurrently (Miles, Huberman, & Saldaña, 2014). Data analysis will be performed manually with transcribed data, field notes and memos organized as Microsoft Word Documents. First, audio recordings will be carefully compared to the written transcripts to ensure accurate transcription. Transcripts will be corrected as needed prior to analysis. Next, transcripts will first be read in their entirety and summarized to get a sense of the whole. Next, preliminary codes will be assigned to data (Saldaña, 2016). An initial list of codes derived from the FMSF will be used. As transcripts are read passages will be coded using the framework derived codes if appropriate. New codes will be created for passages not fitting within the initial framework derived codes (Hsieh & Shannon, 2005). As data is collected and analyzed, codes will be adjusted and refined. A codebook will be kept as a way to organize codes (Saldaña, 2016). Transcripts will then be analyzed using the codes to cluster data into similar categories (Miles et al., 2014). Data will be compared within and across-cases. Within-case data analysis will allow for an understanding of the individual and family experiences, while across-case analysis will allow for comparisons to be made between families (Ayres, Kavanaugh, & Knafl, 2003). Field notes taken immediately following interviews will be reviewed during the data analysis process. Field notes will include the researcher's observations during interviews and thoughts regarding the interaction (Saldaña, 2016). Observations may include body language, facial expressions, interactions and observations related to the environment. Additionally, analytic memos will be written as a way for the researcher to reflect on the data and analysis process (Saldaña, 2016). The researcher will note feelings and insights as analytic memos as a way to document decisions made regarding

analysis and keep the researcher mindful of thoughts and personal feelings that emerge during the analysis process. These memos will be part of the audit trail.

Trustworthiness

In this study the four components of trustworthiness (credibility, transferability, dependability and confirmability) will be addressed in several ways. Credibility will be addressed by comparing data derived from interviews and researcher observations, peer debriefing with members of the dissertation committee and member checks (Patton, 1999). The researcher is the instrument in naturalistic inquiry (Lincoln & Guba, 1985) thus it is essential for the interviewer to be engaged during interviews. The researcher will be attentive to participants taking minimal notes during interviews and documenting field notes shortly after interviews are over. The researcher will meet with members of the dissertation committee experienced in qualitative research, family research and chronic disease management to discuss the data collection, analysis and findings as the study progresses. Member checks will be done with 2-4 study participants who agree to provide feedback regarding the conclusions proposed by the researcher. An effort will be made to include both primary caregivers and additional family participants in member checks. Transferability will be established through providing rich description based on interview data and researcher observations. The researcher will be responsible for providing enough detail for those reading the results to make a decision regarding transferability of the research. In order to elicit rich data purposive sampling will be used (Lincoln & Guba, 1985). Dependability will be addressed by reviewing the research process with members of the dissertation committee. Confirmability will be addressed through providing an audit trail (Lincoln & Guba, 1985). The audit trail will consist of the transcribed data, field notes, analytic memos and notes related to the process of data analysis. In addition to being part

of the audit trail, memos will be used as a way for the researcher to reflect on the data and analysis process.

Anticipated Challenges

There are potential challenges that have been considered when planning this study. Families experiencing social disadvantage are likely facing multiple stressors that may influence their ability or desire to participate in a research study. Participants will be recruited from multiple sites in an attempt to enroll enough participants to reach data saturation. Interviews will be conducted at a time and location that is convenient for the participants. Spanish has been identified as the primary language of many of the clients at the recruitment sites. As a result, interviews will be offered in English and Spanish through the use of an interpreter.

Human Subjects Considerations

The researcher will seek study approval by the University of Massachusetts Institutional Review Board (IRB). The PI will have current Collaborative Institutional Training Initiative (CITI) human subjects online training.

There are no anticipated physical risks associated with participating in this study. There is a chance that participants will become emotionally upset when discussing their child's health condition or challenges their family might experience. This risk will be included in the informed consent and reviewed with participants. Consent and assent will also inform participants that their participation in the study is completely voluntary and they may choose to not answer questions for any reason or withdraw from the study at any time. Written materials including recruitment flyers, study fact sheet and consent/assent information will be available in both English and Spanish. Materials will use simple language whenever possible considering the unknown literacy level of potential participants. In the event that individuals or families have

questions regarding their child's condition or treatment, participants will be referred to their child's primary care physician (PCP) or licensed independent practitioner (LIP). In the event that families do not have access to a PCP or LIP for the child with asthma, they will be given information regarding the low cost or free clinics in Worcester. There are no anticipated financial risks associated with study participation. Interviews will be conducted at a time that is convenient for participants so that they do not miss work.

The researcher will review informed consent with all participants over the age of 18 and with emancipated minors, answer any questions and obtain verbal consent prior data collection. For minors (ages 13-17 years) participating in the study, verbal consent will be obtained from one parent or legal guardian and verbal assent will be obtained from the child. If either the parent does not consent or the child does not provide assent, the child will be excluded from the study. A waiver of documentation of consent will be requested from the IRB. If written consent/assent is required forms will be stamped with an expiration date and stored in a locked file in the Graduate School of Nursing (GSN) for the period of time required by the institution. Although anonymity and confidentiality can never be fully guaranteed, every reasonable effort will be made to protect the privacy of the participants.

Participants will be provided with a $20 gift card of their choosing to Walmart or Target as a small token of appreciation for participating in the research study. Individuals who participate in member checks will receive an additional $20 gift card to the previously mentioned stores.

Conclusion

This qualitative descriptive study will add to the current body of asthma literature by exploring the experience of managing a child's asthma from the family perspective, paying

particular attention to the contextual influences that may contribute to family asthma management. Asthma is a potentially life threatening condition which causes airway inflammation and can lead to respiratory failure. Children who are living in poverty and/or members of certain racial and ethnic groups are disproportionately affected by asthma. Social disadvantage compounds the already difficult task of managing a child's chronic health condition. In addition to the contextual factors described in the FMSF, social and environmental factors associated with poor asthma outcomes but not currently described in the FMSF will also be explored in relation to family management. The narratives of participants will inform nursing practice for those working with families managing a child's asthma in the context of social disadvantage.

References

Akinbami, L. J., Moorman, J. E., Bailey, C., Zahran, H. S., King, M., Johnson, C. A., & Liu, X. (2012). Trends in asthma prevalence, health care use, and mortality in the united states, 2001-2010. *NCHS Data Brief, (94)*(94), 1-8.

Akinbami, L. J., Simon, A. E., & Rossen, L. M. (2016). Changing trends in asthma prevalence among children. *Pediatrics, 137*(1), 2354. Epub 2015 Dec 28. 10.1542/peds.2015-2354 [doi]

Akinbami, L. J., Simon, A. E., & Schoendorf, K. C. (2016). Trends in allergy prevalence among children aged 0-17 years by asthma status, united states, 2001-2013. *The Journal of Asthma : Official Journal of the Association for the Care of Asthma, 53*(4), 356-362. 10.3109/02770903.2015.1126848 [doi]

Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research, 13*(6), 871-883. 10.1177/1049732303013006008 [doi]

Barakat, L. P. (2012). Advancing the family management style framework: Incorporating social ecology. *Journal of Family Nursing, 18*(1), 5-10. 10.1177/1074840711430665 [doi]

Barnett, S. B., & Nurmagambetov, T. A. (2011). Costs of asthma in the united states: 2002-2007. *The Journal of Allergy and Clinical Immunology, 127*(1), 145-152. 10.1016/j.jaci.2010.10.020 [doi]

Beck, A. F., Huang, B., Chundur, R., & Kahn, R. S. (2014). Housing code violation density associated with emergency department and hospital use by children with asthma. *Health Affairs (Project Hope), 33*(11), 1993-2002. 10.1377/hlthaff.2014.0496 [doi]

Beck, A. F., Huang, B., Simmons, J. M., Moncrief, T., Sauers, H. S., Chen, C., . . . Kahn, R. S. (2014). Role of financial and social hardships in asthma racial disparities. *Pediatrics, 133*(3), 431-439. 10.1542/peds.2013-2437 [doi]

Braveman, P. (2014). What are health disparities and health equity? we need to be clear. *Public Health Reports (Washington, D.C.: 1974), 129 Suppl 2*, 5-8. 10.1177/00333549141291S203 [doi]

Braveman, P., & Gottlieb, L. (2014). The social determinants of health: It's time to consider the causes of the causes. *Public Health Reports (Washington, D.C.: 1974), 129 Suppl 2*, 19-31. 10.1177/00333549141291S206 [doi]

Braveman, P. (2006). Health disparities and health equity: Concepts and measurement. *Annual Review of Public Health, 27*, 167-194. 10.1146/annurev.publhealth.27.021405.102103

Cashin, G. H., Small, S. P., & Solberg, S. M. (2008). The lived experience of fathers who have children with asthma: A phenomenological study. *Journal of Pediatric Nursing, 23*(5), 372-385. 10.1016/j.pedn.2007.08.001 [doi]

Chen, E., Shalowitz, M. U., Story, R. E., Ehrlich, K. B., Manczak, E. M., Ham, P. J., . . . Miller, G. E. (2017). Parents' childhood socioeconomic circumstances are associated with their

children's asthma outcomes. *The Journal of Allergy and Clinical Immunology, 140*(3), 835.e2. S0091-6749(17)30031-3 [pii]

Chen, E., Strunk, R. C., Trethewey, A., Schreier, H. M., Maharaj, N., & Miller, G. E. (2011). Resilience in low-socioeconomic-status children with asthma: Adaptations to stress. *The Journal of Allergy and Clinical Immunology, 128*(5), 970-976. 10.1016/j.jaci.2011.06.040 [doi]

Deatrick, J. A. (2017). Where is "family" in the social determinants of health? implications for family nursing practice, research, education, and policy. *Journal of Family Nursing,* , 1074840717735287. 10.1177/1074840717735287 [doi]

Deatrick, J. A., Thibodeaux, A. G., Mooney, K., Schmus, C., Pollack, R., & Davey, B. H. (2006). Family management style framework: A new tool with potential to assess families who have children with brain tumors. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses, 23*(1), 19-27. 10.1177/1043454205283574 [doi]

Dowell, J. A. (2015). Experiences, functioning and needs of low-income african american mothers of children with asthma. *Journal of Pediatric Nursing, 30*(6), 842-849. 10.1016/j.pedn.2015.04.003 [doi]

Fisher, L., Chesla, C. A., Bartz, R. J., Gilliss, C., Skaff, M. A., Sabogal, F., . . . Lutz, C. P. (1998). The family and type 2 diabetes: A framework for intervention. *The Diabetes Educator, 24*(5), 599-607. 10.1177/014572179802400504 [doi]

Gibson-Young, L., Turner-Henson, A., Gerald, L. B., Vance, D. E., & Lozano, D. (2014). The relationships among family management behaviors and asthma morbidity in maternal caregivers of children with asthma. *Journal of Family Nursing, 20*(4), 442-461. 10.1177/1074840714552845 [doi]

Gilliss, C. L. (1983). The family as a nunit of analysis: Strategies for the nurse researcher. *Advances in Nursing Science, 5*(3), 50-59.

Grineski, S. (2008). Coping with asthma in the central city: Parental experiences with children's health care. *Journal of Health Care for the Poor and Underserved, 19*(1), 227-236. 10.1353/hpu.2008.0025 [doi]

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. 15/9/1277 [pii]

International Council of Nurses. (2012). The ICN code of ethics for nurses. Retrieved from http://www.icn.ch/publications/international-nursing-review-inr/

Keet, C. A., Matsui, E. C., McCormack, M. C., & Peng, R. D. (2017). Urban residence, neighborhood poverty, race/ethnicity, and asthma morbidity among children on medicaid. *The Journal of Allergy and Clinical Immunology, 140*(3), 822-827. S0091-6749(17)30341-X [pii]

Keet, C. A., McCormack, M. C., Pollack, C. E., Peng, R. D., McGowan, E., & Matsui, E. C. (2015). Neighborhood poverty, urban residence, race/ethnicity, and asthma: Rethinking the

inner-city asthma epidemic. *The Journal of Allergy and Clinical Immunology, 135*(3), 655-662. 10.1016/j.jaci.2014.11.022 [doi]

Kenyon, C. C., Melvin, P. R., Chiang, V. W., Elliott, M. N., Schuster, M. A., & Berry, J. G. (2014). Rehospitalization for childhood asthma: Timing, variation, and opportunities for intervention. *The Journal of Pediatrics, 164*(2), 300-305. 10.1016/j.jpeds.2013.10.003 [doi]

Knafl, K. A., & Deatrick, J. A. (1990). Family management style: Concept analysis and development. *Journal of Pediatric Nursing, 5*(1), 4-14.

Knafl, K. A., & Deatrick, J. A. (2003). Further refinement of the family management style framework. *Journal of Family Nursing, 9*(3), 232-256. 10.1177/1074840703255435

Knafl, K. A., Deatrick, J. A., & Havill, N. L. (2012). Continued development of the family management style framework. *Journal of Family Nursing, 18*(1), 11-34. 10.1177/1074840711427294 [doi]

Kopel, L. S., Phipatanakul, W., & Gaffin, J. M. (2014). Social disadvantage and asthma control in children. *Paediatric Respiratory Reviews, 15*(3), 256-263. 10.1016/j.prrv.2014.04.017 Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/24928775

Kosny, A., MacEachen, E., Lifshen, M., & Smith, P. (2014). Another person in the room: Using interpreters during interviews with immigrant workers. *Qualitative Health Research, 24*(6), 837-845. 1049732314535666 [pii]

Kranjac, A. W., Kimbro, R. T., Denney, J. T., Osiecki, K. M., Moffett, B. S., & Lopez, K. N. (2017). Comprehensive neighborhood portraits and child asthma disparities. *Maternal and*

Child Health Journal, 21(7), 1552-1562. 10.1007/s10995-017-2286-z Retrieved from https://doi.org/10.1007/s10995-017-2286-z

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Mangini, L. D., Hayward, M. D., Dong, Y. Q., & Forman, M. R. (2015). Household food insecurity is associated with childhood asthma. *The Journal of Nutrition, 145*(12), 2756-2764. 10.3945/jn.115.215939 [doi]

Martin, M., Beebe, J., Lopez, L., & Faux, S. (2010). A qualitative exploration of asthma self-management beliefs and practices in puerto rican families. *Journal of Health Care for the Poor & Underserved, 21*(2), 464-474. 10.1353/hpu.0.0285 Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=105203704&site=ehost-live

McDaniel, M. K., & Waldfogel, J. (2012). Racial and ethnic differences in the management of childhood asthma in the united states. *The Journal of Asthma : Official Journal of the Association for the Care of Asthma, 49*(8), 785-791. 10.3109/02770903.2012.702840 [doi]

Mehta, N. K., Lee, H., & Ylitalo, K. R. (2013). Child health in the united states: Recent trends in racial/ethnic disparities. *Social Science & Medicine (1982), 95*, 6-15. 10.1016/j.socscimed.2012.09.011 [doi]

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Los Angeles: Sage.

National Asthma Education and Prevention Program. (2007). *Expert panel report 3: Guidelines for the diagnosis and management of asthma.* ().U.S. Department of Health and Human Services, National Institutes of Health. Retrieved from https://www.nhlbi.nih.gov/files/docs/guidelines/asthgdln.pdf

Patel, M. R., Brown, R. W., & Clark, N. M. (2013). Perceived parent financial burden and asthma outcomes in low-income, urban children. *Journal of Urban Health : Bulletin of the New York Academy of Medicine, 90*(2), 329-342. 10.1007/s11524-012-9774-7 [doi]

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*(5 Pt 2), 1189-1208.

Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Los Angeles: Sage.

Sandelowski, M. (2010). What's in a name? qualitative description revisited. *Research in Nursing & Health, 33*(1), 77-84. 10.1002/nur.20362 [doi]

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334-340. AID-NUR9>3.0.CO;2-G Retrieved from http://dx.doi.org/10.1002/1098-240X(200008)23:43.0.CO;2-G

Santos, H. P.,Jr, Black, A. M., & Sandelowski, M. (2015). Timing of translation in cross-language qualitative research. *Qualitative Health Research, 25*(1), 134-144. 10.1177/1049732314549603 [doi]

Sato, A. F., Kopel, S. J., McQuaid, E. L., Seifer, R., Esteban, C., Coutinho, M. T., . . . Koinis-Mitchell, D. (2013). The home environment and family asthma management among

ethnically diverse urban youth with asthma. *Families, Systems & Health : The Journal of Collaborative Family Healthcare, 31*(2), 156-170. 10.1037/a0032462 [doi]

Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for, 2020. (2010). Healthy people 2020: An opportunity to address societal determinants of health in the united states. Retrieved from http://www.healthypeople.gov/2010/hp2020/advisory/societaldeterminantshealth.htm

Squires, A. (2008). Language barriers and qualitative nursing research: Methodological considerations. *International Nursing Review, 55*(3), 265-273. 10.1111/j.1466-7657.2008.00652.x [doi]

Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook, 53*(3), 127-133. S0029655405000643 [pii]

Temple, B. (2002). Crossed wires: Interpreters, translators, and bilingual workers in cross-language research. *Qualitative Health Research, 12*(6), 844-854. 10.1177/104323020120060l0 Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12109728

U.S. Department of Health and Human Services. (2008). *The secretary's advisory committee on national health promotion and disease prevention objectives for 2020. phase I report: Recommendations for the framework and format of healthy people 2020.* (). Retrieved from http://www.healthypeople.gov/sites/default/files/PhaseI_0.pdf

U.S. Department of Health and Human Services. (2014). Healthy people 2020: Social determinants of health. Retrieved from https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health

U.S. Small Business Administration.Social disadvantage eligibility. Retrieved from http://www.sba.gov/content/social-disadvantage-eligibility

Williams, D. R., Sternthal, M., & Wright, R. J. (2009). Social determinants: Taking the social context of asthma seriously. *Pediatrics, 123 Suppl 3*, 174. 10.1542/peds.2008-2233H [doi]

Willis, D. G., Sullivan-Bolyai, S., Knafl, K., & Cohen, M. Z. (2016). Distinguishing features and similarities between descriptive phenomenological and qualitative description research. *Western Journal of Nursing Research, 38*(9), 1185-1204. 10.1177/0193945916645499 [doi]

Summary of Changes from the Proposal

The research approach, a qualitative descriptive study, was executed as outlined in the research proposal with the following changes:

1. The recruitment sites listed in the research proposal were not used. Additional recruitment sites were added. Due to slow enrollment an "Authorization to Contact Form" was used to collect contact information from participants who indicated interest in participating in the study. Site staff collected the "Authorization to Contact Form" which was then faxed or sent via encrypted email to the PI. The PI then contacted the potential participants according to the instructions on the form.
2. An interview guide specifically for participants under the age of 18 years old was added. The interview guide is similar to the family member interview guide, however questions that were not age appropriate were eliminated.
3. Several changes were made due to the COVID-19 pandemic which occurred during study recruitment and data collection.

- Face to face interviews were not possible due to state guidelines and University policy. Interviews that occurred after March 13, 2021 were conducted via telephone.
- A recruitment flyer was shared via social media (Facebook) due to the closure and/or limited client visits at recruitment sites during the pandemic. The recruitment flyer was shared on my personal page and also posted to parent asthma support groups with permission from the page administrator. This recruitment strategy resulted in recruitment of participants outside of central Massachusetts.
- Because participants began discussing the COVID-19 pandemic during interviews, a question and probes were added to the interview guide related to COVID-19.

Slide Presentation

Childhood Asthma: Contextual Influences Affecting Family Management

Melissa A. Dunn
University of Massachusetts Medical School
Graduate School of Nursing
April 15, 2021

Background and Significance

- 5.5 million children in the United States have asthma (CDC, 2020)
  - 3.8% of children 0-4 years-old (CDC, 2020)
  - 8.6% of children 5-14 years-old (CDC, 2020)
- Disparities linked to race, ethnicity and socioeconomic status
  - Severity (Akinbami et al., 2016; Mehta et al., 2013)
  - ED utilization & hospitalization (Keet et al., 2017; Kenyon et al., 2014; Mehta et al., 2013)
  - Readmission (Beck et al, 2014)
  - Use of preventative measures (McDaniel & Waldfogel, 2012)

Background and Significance

- Housing quality is associated with ED use (Hughes et al., 2017)
- Indoor and outdoor air quality are associated with asthma prevalence and outcomes (DeSario et al., 2013; George et al., 2017; WHO, 2018)
- Relationships with providers and school nurses have been identified as important for providing support and education (Bellin et al., 2018)
- The quality of family relationship influences asthma response (Sato et al., 2013
- Asthma control worse when mothers work outside of the home (Gibson-Young et al., 2014)

The Gap

There is little nursing research examining the ways in which families experience and respond to contextual factors commonly associated with asthma outcomes.

Framework

The Family Management Style Framework (Knafl, Deatrick & Havill, 2012) guided this study

Purpose

To explore the the way(s) in which family management of childhood asthma is affected by contextual influences as described in the Family Management Style Framework (FMSF) and to explore additional sociocultural factors that affect family asthma management.

Specific Aims

1. To describe the everyday experiences of childhood asthma management within families

2. To explore the way(s) in which family management of childhood asthma is affected by contextual influences (social network, care providers, systems and resources) as described in the Family Management Style Framework

3. To explore additional sociocultural factors (supported by the literature but not currently described in the FMSF) that affect asthma management in families

Methods: Design and Setting

- Qualitative descriptive design (Sandelowski, 2000; 2010; Willis et al., 2016)
- Purposive sampling (Lincoln & Guba, 1985)
  - Pre COVID-19 pandemic
    - Recruited from a Pediatric Pulmonology Clinic and community-based site in the Northeast
  - During the COVID-19 pandemic
    - Social media platform (Facebook)

Inclusion Criteria

- Primary caregiver (over the age of 16) for a child between the ages of 2-12 years old with a diagnosis of asthma
- Additional family member participating in care (minimum age of 13 years)
- Able to speak English or Spanish

Methods: Procedures

- Human subject protection
  - Institutional Review Board (IRB) approval was obtained from the University of Massachusetts Medical School IRB
- In-person recruitment
  - Authorization to contact
- Recruitment flyer shared via social media
  - Parent support group
  - Sample beyond New England

Methods: Procedures

- Fact sheet, verbal consent
- Demographic data
- Interviews
  - Flexible interview guide
  - Face-to-face and telephone interviews
  - Audio recorded
  - 25-53 minutes
- Recruitment ended when data saturation was reached
- $20 gift card compensation

Methods: Data Analysis

- Concurrent data collection and analysis (Miles et al., 2005)
- Professionally transcribed verbatim and checked for accuracy
- Directed content analysis (Hsieh & Shannon, 2005)
  - Initial set of codes derived from the FMSF
  - Additional codes generated
- Refinement of codes
- Patterns noted and codes clustered (Willis et al., 2016)
- Themes emerged

Trustworthiness

- Peer debriefing
- Member checks
- Audit trail
- Reflexive journaling
- Field notes

(Lincoln & Guba, 1985)

Characteristics of Participants (N=14)

Characteristics	n	*M*	Range
Age (years)		39.57	25-70 years
Gender			
Female	14		
Ethnicity			
Hispanic	2		
Not Hispanic	11		
Other	1		
Race			
Black	2		
Caucasian	11		
Other	1		
Family Role			
Parent	12		
Legal Guardian	2		
Marital Status			
Married	11		
Single	2		
Divorced	1		

Characteristics of the Participants (Continued)

Characteristics	n	*M*	Range
Employment Status			
Full time	5		
Part time	2		
Unemployed	6		
Retired	1		
Years of formal education		15.42	12-22 years
Difficulty paying for basics			
Somewhat hard	4		
Not very hard	10		
Annual family income			
<$20,000	1		
$20,000-$30,000	1		
$30,000-$40,000	2		
>$50,000	10		

Characteristics of the Child with Asthma

Characteristics	n	*M*	Range
Age		7.26	3-11 years
Gender Male Female	 7 7		
Years since diagnosis	14	3.71	1-9 years

Results

Consistent with the FMSF	**Findings Beyond the FMSF**
1. Social Networks	4. Environment
2. Care Providers & Systems	5. Emerging Threats to Health
3. Resources	6. Work-Life Conditions

Social Network

"So, like, if he's doing better, but not quite where I feel like he needs to be in school, she'll [grandmother] watch him for us. I think it really makes her nervous."

"I worry that they may not understand, what is happening…my concern is somebody else not getting, seeing what should be done."

Social Network

"…I think what's been helpful is just to see that there are so many parents dealing with it as well. So, it's more of an emotional thing. I don't, I wouldn't go there for, fact-based, (laugh), science recommendations. That I'll get from the doctor, but it's more of an emotional support of being able to see that I have the same questions that other people do, and that we're all kind of, a lot of us are dealing with it."

Care Providers & Systems: Healthcare Providers

"…when he gets sick, I usually don't call the pulmonary doctor to make an appointment, I call his pediatric doctor…and, they already know me. So once I say his name and what's going on they want to see him right away."

"he continues to be very supportive and listens to us and acknowledges what we're saying and teaches us."

"I have felt that they make you feel bad as a parent, that you should have seen the signs sooner…"

Care Providers & Systems: School and Daycare

"…there's not a designated school nurse, but there are really helpful office staff…so they keep an eye on him, and then I've informed the teacher"

"I have the nurse let me know when she gives her the medication, so anytime during school so I can plan it out…she'll send me an email or even sometimes she's come up, like when I pick up the girls, she's come up and said something…You know-this happened today and just to let you know."

Resources: Financial

"So let's say he's out of school or the program for a whole week, I still have to pay for those days."

"…so our biggest challenge is that our insurance does not cover, his maintenance medication pretty much at all. Each month we spend probably $275 on his maintenance inhaler and then his rescue inhaler is $175 and that one lasts longer than a month."

Resources: Health Insurance

"It's never cost. It's never cost us anything. The only thing I had to buy is the saline anything else that he's ever had, has always been by prescription."

"…it's not covered unless medically necessary and I was like, "Well, it is medically necessary (laughs) otherwise the doctor wouldn't be prescri-…" Like so it's going back and forth on them on like what their logic was…at the end of the day, I can still afford it, but I just think that the system is broken here."

Resources: Health Insurance

"It is quite expensive and before I switched insurance, for example, an emergency room visit was $500. And so there were certainly times where I was questioning, like, "Should we not go yet?" Because I was think-the $500. And so, that's a horrible feeling to have when you're at home, you can see your child struggling and you want to care…and then…this is going to be another $500 visit…the cost of it will make you pause for a moment and think, "Is he sick enough to incur this cost?"

Environment: Household

"…unfortunately, at the time of diagnosis we had two dogs and two indoor/outdoor cats, and we decided as a family that we were going to not get rid of them, to see if we could treat the attacks, or the, the symptoms with medication first. And then if we couldn't keep things under control and she couldn't find relief, that we would, we would think about re-homing."

Environment: Outdoor

"We also generally will watch the wind. Um, just because we don't know what it is that blows around, but if there's enough wind, we-we generally just don't go outside."

"…we live in the middle of the country. So on acres of land when people are doing all sorts of farm work. So I feel like that's maybe a trigger for him."

Emerging Threats to Health: Global Climate

"we, unfortunately, often have fires, and the times that we've had fires, I've noticed that he then has quite a reaction to the smoke soon after that."

"So we got an email from our, from her pulmonologist, last week saying that, you know, this is coming in, for those respiratory compromised kids. We just want to be prepared. And it really did. She played outside for 15 minutes yesterday and could not stop coughing and needed albuterol."

Emerging Threats to Health: COVID-19

"…this last time he had, uh, asthma flare, I needed, I wanted to take him in because he was breathing fast. He was coughing nonstop. He was throwing up mucus. But because of his symptoms, I had to take him to a respiratory clinic. I couldn't take him to his doctor that he knows and who knows him. I had to take him to this clinic that they set up where only people with symptoms go. I knew that it was asthma. I knew that it was a flare, but I had to take him into a building where I knew people had COVID and I knew people who were really sick were there. I didn't like that at all."

Emerging Threats to Health: COVID-19

"…because of the virus, they are not able to do breathing treatments this fall, so through the school year. And so she's like, "I think you should, talk to your doctor and- and your husband and just get a good plan because if something happens, we can't help her besides calling 911."

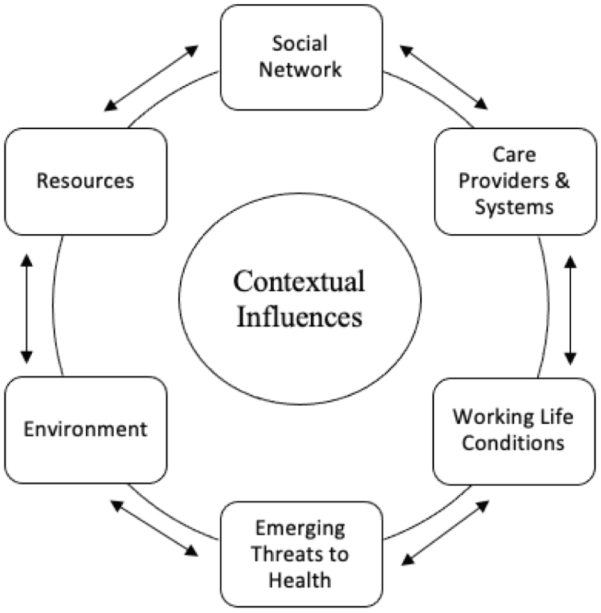
Work-Life Conditions

"…they understand that when you have a son with asthma and you have to call out, you have to call out"

"Well, um, it forced us to decide to have one parent stay home. So, just because of logistics and income-wise, I decided to keep working, and my husband decided to be a stay-at-home dad. But then he works on the weekends."

Interrelated Contextual Influences

- Limiting social interactions during the COVID-19 pandemic
- Financial resources limiting modifications to the home
- Relying on the support of providers to help educate extended family members



Discussion and Nursing Implications

- Findings support the contextual influences described in the FMSF
- The contextual influences are interrelated demonstrating the complexity of family asthma management
- Opportunity for nurses to engage in education, health policy and further research
  - Policy implications related to cost of prescription medications/treatment and environment
  - *Emerging Threats to Health* may have a temporal component-further research

Limitations and Strengths

- Female primary caregivers interviewed at a single point in time
- Findings are specific to family asthma management

- Recruitment and logistics during a pandemic
- Broader geographical representation across North America

Conclusions

- The findings support additional contextual influences specific to asthma management
- *Environment, Work-Life Conditions* and *Emerging Threats to Health* move closer to a better understanding of the connection between family asthma management and the social determinants of health
- Nurses working with families should consider the ways in which contextual influences affect asthma management when planning interventions.

Acknowledgements

Dissertation Committee
Donna Perry, PhD, RN
Kenneth Peterson, PhD, FNP-BC
Susan Sullivan-Bolyai, DNSc, CNS, RN, FAAN
GSN Faculty & Staff
Physicians, Nurses and Staff at Recruitment Sites
PhD Cohort
Friends and Colleagues
STTI, Iota Phi-at-large Research Grant
My Family!

Selected References

Akinbami, L. J., Simon, A. E., & Rossen, L. M. (2016). Changing trends in asthma prevalence among children. *Pediatrics, 137*(1), Article e20152354. https://doi.org/10.1542/peds.2015-2354

Centers for Disease Control and Prevention, National Center for Environmental Health. (2020). *Most recent national asthma data*. https://www.cdc.gov/asthma/most_recent_national_asthma_data.htm

Chen, E., Hayen, R., Le, V., Austin, M. K., Shalowitz, M. U., Story, R. E., & Miller, G. E. (2019). Neighborhood social conditions, family relationships, and childhood asthma. *Pediatrics, 144*(2). https://doi.org/10.1542/peds.2018-3300

George, M., Bruzzese, J., & Matura, L. A. (2017). Climate change effects on respiratory health: Implications for nursing. *Journal of Nursing Scholarship, 49*(6), 644-652.

Gibson-Young, L., Turner-Henson, A., Gerald, L. B., Vance, D. E., & Lozano, D. (2014). The relationships among family management behaviors and asthma morbidity in maternal caregivers of children with asthma. *Journal of Family Nursing, 20*(4), 442-461.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-128. https://doi.org/10.1177/1049732305276687

Keet, C. A., Matsui, E. C., McCormack, M. C., & Peng, R. D. (2017). Urban residence, neighborhood poverty, race/ethnicity, and asthma morbidity among children on Medicaid. *The Journal of Allergy and Clinical Immunology, 140*(3), 822-827. https://doi.org/10.1016/j.jaci.2017.01.036

Selected References

Kenyon, C. C., Melvin, P. R., Chiang, V. W., Elliott, M. N., Schuster, M. A. & Berry, J. G. (2014). Rehospitalization for childhood asthma: Timing, variation, and opportunities for intervention. *The Journal of Pediatrics, 164*(2), 300-305. https://doi.org/10.1016/j.jpeds.2013.10.003

Knafl, K. A., & Deatrick, J. A. (2003). Further refinement of the family management style framework. *Journal of Family Nursing, 9*(3), 232-256. http://doi.org/10.1177/1074840703255435

Knafl, K. A., Deatrick, J. A., & Havill, N. L. (2012). Continued development of the Family Management Style Framework. *Journal of Family Nursing, 18*(1), 11-34. https://doi.org/10.1177/1074840711427294

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Mehta, N. K., Lee, H., & Ylitalo, K. R. (2013). Child health in the United States: Recent trends in racial/ethnic disparities. *Social Science & Medicine, 95*(2013), 6-15. https://doi.org/10.1016/j.socscimed.2012.09.011

Willis, D. G., Sullivan-Bolyai, S., Knafl, K. & Cohen, M. A. (2016). Distinguishing features and similarities between descriptive phenomenological and qualitative description research. *Western Journal of Nursing Research, 38*(9), 1185-1204. https://doi.org/10.1177/0193945916645499

World Health Organization. (2018). Air pollution and child health: Prescribing clean air [Summary]. https://www.who.int/ceh/publications/air-pollution-child-health/en/

Dissemination Plan

The primary description of this dissertation work was submitted as a manuscript on May 24, 2021 to *The Journal of Family Nursing* for review and consideration for publication.

Appendices

Appendix A
Flexible Interview Guide- Parent/Guardian

Specific Aim Addressed	**Conceptual Underpinnings of Theoretical Framework**	**Interview Questions**	**Probes**
Aim #1: To describe the everyday experiences of childhood asthma management within families experiencing social disadvantage	Definition of the Situation	Describe a typical day managing your child's asthma.	Who does what? How much time does asthma management take? How do you incorporate this into daily life?
Aim #1	Family Focus • Family Unit Functioning	How does managing your child's asthma affect your family?	Does it affect your work (or school) attendance? How so? How does it affect your other responsibilities?
Aim #2 To explore the way(s) in which family management of childhood asthma is affected by contextual influences (social network, care providers and systems and resources) as described in the Family Management Style Framework.	Contextual Influence • Social Network	Tell me about the people who help you take care of your child with asthma? Who gives you advice as to how to manage your child's asthma?	In what ways do they help? How did this person/people come to help? What specifically do they do to help? Who taught them about asthma? How did they learn how to do what they do? Are there any other people who help your family? Do you attend any parent support groups?

Aim #2	Contextual Influence • Care Providers, Healthcare and Education Systems	For preschool and school age children: Is your child in school? Tell me about your experiences with school and managing your child's asthma?	Are teachers, school nurses or other school staff involved in caring for your child? Does your child receive any medical care at school?
Aim #2	Contextual Influence • Care Providers, Healthcare and Education Systems	Tell me about the health care professionals that you interact with to manage your child's asthma?	What are their roles? How do you feel about the care they provide? Do you feel comfortable talking to them about your child's asthma? If satisfied with care-what makes them effective providers? If dissatisfied with care-what could they do differently?
Aim #2	Contextual Influence • Resources	Has there been a time when you were concerned about your family's ability to provide necessary asthma treatment due to concerns about money? • How did your	Do you ever need to take time off of work when your child is sick because of their asthma? How does taking time off

		family deal with that challenge?	affect your job or family? Did you use any community resources? How did you find them?
Aim #2	Contextual Influence • Resources	If insured- How does having health insurance affect your ability to take care of your child? If uninsured- Tell me about how you access health care?	Do you ever have difficulty getting your child's asthma medications? Tell me more about that. Have you ever had trouble finding a doctor for your child?
Aim #3 To explore additional sociocultural factors (supported by the literature but not currently described in the FMSF) that affect asthma management in families experiencing social disadvantage.		Tell me about where you live? Is there anything in or around your home that causes your child to wheeze or have trouble breathing? Is there anything in your neighborhood that causes your child to wheeze or have trouble breathing? Can you think of anything that makes managing your child's asthma difficult? How has the way you manage asthma changed since the COVID-19 virus became a concern? How does your culture influence how you manage asthma?	How do you think where you live affects your child's asthma? Describe how? How is your family handling the changes to your daily lives?

		Would you like to add anything else?	

Appendix B

Flexible Interview Guide- Family Member

Specific Aim Addressed	Conceptual Underpinnings of Theoretical Framework	Interview Questions	Probes
Aim #1: To describe the everyday experiences of childhood asthma management within families experiencing social disadvantage	Definition of the Situation	Describe a typical day managing your family member's asthma?	Who does what? How much time does asthma management take? How do you incorporate this into daily life?
Aim #1	Family Focus • Family Unit Functioning	How does having a family member with asthma affect your family?	Does it affect work/school attendance? How so? How does it affect your other responsibilities ?
Aim #2 To explore the way(s) in which family management of childhood asthma is affected by contextual influences (social network, care providers and systems and resources) as described in the Family Management Style Framework.	Contextual Influence • Social Network	Tell me about the people who help take care of the child(ren) with asthma? Who gives you advice as to how to manage your family member's asthma?	In what ways do they assist? How did this person/people come to help? Are there any other people who help your family? Has anyone in your family attended asthma support groups? How did you learn about caring for someone with asthma?
Aim #2	Contextual Influence	For preschool and school	Are teachers,

	• Care Providers, Healthcare and Education Systems	age children: Tell me about your experiences with school and managing asthma?	school nurses or other school staff involved in caring for your family member? Does your family member receive any medical care at school?
Aim #2	Contextual Influence • Care Providers, Healthcare and Education Systems	Tell me about your interactions with healthcare providers related to asthma management?	Who have you interacted with? How do you feel about the care they provide? Do you feel comfortable talking with them? If satisfied with care-what makes them effective providers? If dissatisfied with care-what could they do differently?
Aim #2	Contextual Influences • Resources	Has there been a time when you were concerned about your family's ability to provide necessary asthma treatment due to concerns about money? How did your family deal with that challenge?	Did you use any community resources? How did you find them?
Aim #2	Contextual	If insured- How does	Does your

	Influences • Resources	having health insurance affect your family's ability to manage asthma? In uninsured- Tell me about how your family accesses health care?	family ever have trouble getting asthma medications? Tell me more about that? Has your family ever had trouble finding a doctor that treats asthma?
Aim #3 To explore additional sociocultural factors (supported by the literature but not currently described in the FMSF) that affect asthma management in families experiencing social disadvantage.		Tell me about where you live? Is there anything in or around your home that causes your family member to wheeze or have trouble breathing? Is there anything in your neighborhood that causes your family member to wheeze or have trouble breathing? Can you think of anything that makes managing asthma difficult? How has the way you manage asthma changed since the COVID-19 virus became a concern? Does your culture influence how you manage asthma? Would you like to add anything else?	How do you think where you live affects your family member's asthma? Describe how? How is your family handling the changes to your daily lives?

Appendix C

Flexible Interview Guide- Family Member (under age 18 years old)

Specific Aim Addressed	**Conceptual Underpinnings of Theoretical Framework**	**Interview Questions**	**Probes**
Aim #1: To describe the everyday experiences of childhood asthma management within families experiencing social disadvantage	Definition of the Situation	Describe a typical day managing your family member's asthma?	Who does what? How much time does asthma management take? How do you incorporate this into daily life?
Aim #1	Family Focus • Family Unit Functioning	How does having a family member with asthma affect your family?	Does it affect work/school attendance? How so? How does it affect your other responsibilities ?
Aim #2 To explore the way(s) in which family management of childhood asthma is affected by contextual influences (social network, care providers and systems and resources) as described in the Family Management Style Framework.	Contextual Influence • Social Network	Tell me about the people who help take care of the child(ren) with asthma? Who gives you advice as to how to manage your family member's asthma?	In what ways do they assist? How did this person/people come to help? Are there any other people who help your family? Has anyone in your family attended asthma support groups? How did you learn about caring for

			someone with asthma?
Aim #2	Contextual Influence • Care Providers, Healthcare and Education Systems	Do you ever go to doctor's appointments with your brother/sister/family member?	What types of appointments have you been to? How do you feel about the care your family member receives? Tell me about what it is like to talk with doctors/nurses or other health providers? How do you feel at the appointments?
Aim #3 To explore additional sociocultural factors (supported by the literature but not currently described in the FMSF) that affect asthma management in families experiencing social disadvantage.		Tell me about where you live? Is there anything in or around your home that causes your family member to wheeze or have trouble breathing? Is there anything in your neighborhood that causes your family member to wheeze or have trouble breathing? Can you think of anything that makes managing asthma difficult?	How do you think where you live affects your family member's asthma? Describe how?

		Does your culture influence how you manage asthma? Would you like to add anything else?	

Appendix D

Demographic Data Collection Instrument (Parent Version)

Date of visit:_____ Participant ID#:_____

Verbal consent obtained: ____ yes ____ no

Participant's age: _____
Gender**:**

_____ male

_____ female

Ethnicity:

_____ Hispanic or Latino

_____ Not Hispanic or Latino
_____ Other
If other, please list: _____
Race:

_____ Caucasian
_____ Black
_____ Asian
_____ American Indian
_____ Other
If other, please list: _____

Role in family:

_____ parent
_____ legal guardian
Marital Status:
_____ Single
_____ Married
_____ Unmarried partners
_____ Divorced
_____ Separated
_____ Widowed

Number of children with asthma living in the home: _____
Age of child with asthma:_____ Gender of child with asthma (circle): male female

Age at diagnosis: _____

Age of child with asthma:_____ Gender of child with asthma (circle): male female

Age at diagnosis: _____

Age of child with asthma:_____ Gender of child with asthma (circle): male female

Age at diagnosis: _____

Age of child with asthma:_____ Gender of child with asthma (circle): male female

Age at diagnosis: _____

Number of adults (18 years) living in your home: _____

Number of children (17 years and younger) living in your home: _____

How many people in your home help with managing your child's asthma:_____

Type of Dwelling:
_____ House
_____ Apartment
_____ Shelter

Employment Status:

_____Full Time

_____Part Time

_____Unemployed

_____ Retired

_____ Student

Number of years of formal education completed: _____
Insurance Status:
____ private insurance
_____public insurance (Medicaid)

_____uninsured
How hard is it for you to pay for the very basics like food, housing, medical care and heating?

Very hard _____ Somewhat hard_____ Not very hard at all_____ Don't know_____

Annual Household Income (optional):

_____ < $20,000
_____ $20,000-$30,000
_____ $30,000-$40,000
_____ >$50,000

Appendix E

Demographic Data Collection Instrument (Family Member)

Date of visit:_____ Participant ID#:_____

Participant's age: _____

Verbal consent obtained (participants 18 years and older): _____ yes _____ no

Parental verbal consent obtained (participants <18 years old): _____ yes _____ no

Verbal assent obtained (participants <18 years old): _____ yes _____ no

Gender**:**

_____ male

_____ female

Role in family:

_____ sibling

_____ grandparent

_____ aunt

_____ uncle

_____ other: _____

Ethnicity:

_____ Hispanic or Latino

_____ Not Hispanic or Latino
_____ Other
If other, please list: _____

Race:

_____ Caucasian
_____ Black

_____ Asian
_____ American Indian
_____ Other
If other, please list: _____

Employment Status:

_____Full Time

_____Part Time

_____Unemployed

_____ Retired

_____ Student

Number of years of formal education completed: _____